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Living with mesothelioma: A qualitative study of the experiences of male military veterans in the UK

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ABSTRACT

Purpose: The UK has the highest incidence of mesothelioma in the world. Evidence in the United States suggests that mesothelioma may disproportionately affect military veterans. However, there has been no investigation of the experience of UK veterans living with mesothelioma. The Military Mesothelioma Experience Study (MiMES) aimed to understand the experience and health/support needs of British Armed Forces personnel/veterans with mesothelioma.

Methods: Semi-structured interviews were conducted with 13 veterans living with mesothelioma, and nine family members of veterans living with mesothelioma. Participants were recruited via charities and asbestos support groups. Data were analysed using thematic analysis.

Results: Participants' experiences are presented using three themes, i) exposure to asbestos and awareness of asbestos related diseases, ii) using military strategies to cope with mesothelioma and iii) preferences for information and support. MiMES indicates that the nature and range of UK military veterans' asbestos exposure is varied and not limited to high risk occupations. Participants' knowledge of asbestos and experience of mesothelioma influenced their experiences of diagnosis. Participants had coping strategies influenced by their military experiences. Assistance in navigating health and military systems was considered beneficial, especially if support was provided by professionals with knowledge or experience of the military. Attributes which may inhibit veterans from seeking professional support are discussed.

Conclusion: MiMES provides insight into how UK military veterans experience and cope with mesothelioma. Key implications focus on the role that Mesothelioma Nurse Specialists, Asbestos Support Groups and veterans groups play in providing acceptable support for UK veterans.

1. Introduction

With nearly 2700 new cases diagnosed each year (Cancer Research UK, 2020) the UK has the highest incidence of mesothelioma in the world. Historically linked to industries like construction and dockyards, mesothelioma is now linked to a range of workplaces and environments (Peto et al., 2009). Mesothelioma mostly affects men over 65 years of age; the only known cause is exposure to asbestos which has usually occurred 15–40 years previously (Health and Safety Executive, 2019).

Mesothelioma is treatable but incurable (British Thoracic Society, 2008). Survival is usually measured in months. Approximately 60% of people diagnosed with mesothelioma will die within a year of diagnosis (Royal College of Physicians, 2020). Mesothelioma is a challenging cancer because of the symptom burden, disease trajectory and mortality rates (Dooley et al., 2010). It is associated with a range of life limiting and debilitating symptoms including breathlessness, pain, cough, lethargy, weight loss and sweating. Studies have reported psychological impacts, including depression, anxiety, low mood, as common (Ball et al., 2016; Dooley et al., 2010; Moore et al., 2010; Sherborne et al., 2020). Often patients enter into complex treatment programs resulting

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in a range of side effects with no guarantee of benefit. The industrial nature of the disease means, in addition to navigating healthcare systems, patients and their family members may have complex benefit and compensation claims to process (Ball et al., 2016).

Previous epidemiological studies have focused predominantly on construction workers and asbestos industry workers, industries with high rates of mesothelioma (Harding and Darnton, 2010; Rake et al., 2009). Evidence from the United States estimates that up to 30% of mesothelioma diagnoses occur in veterans (Siegert et al., 2017). The incidence of mesothelioma amongst people with a UK military background is not reported and there is no data to suggest that veterans in the UK are at an increased risk of developing mesothelioma (Peto et al., 2009). However, reports from the United States suggest there may be a disproportionately high number of veterans living with mesothelioma (Roggli et al., 2009; Till et al., 2019).

Within the UK, the military (or Armed Forces) consists of three professional branches. These are the Army, the Navy and the Royal Air Force (RAF). The impact of a diagnosis of mesothelioma on veterans, both in the UK and internationally, also remains unexplored. However, anecdotal evidence from clinical and legal professionals in the UK indicates that veterans face particular challenges in accessing services and navigating both military and civilian health, legal and welfare systems. In addition, some military processes and systems are separate from those used by civilians, including Armed Forces benefits and compensation schemes. The experience of veterans living with mesothelioma in navigating these systems remains unknown. Additionally, there has been no systematic investigation of the nature of asbestos exposure and impact of mesothelioma on UK military veterans.

In summary, there is a lack of evidence on the experience of UK veterans living with mesothelioma and the additional challenges that they may face. Their support needs are also unknown. The Military Mesothelioma Experience Study (MiMES) was designed to address these evidence gaps and identify related care needs of UK veterans living with mesothelioma. MiMES aimed to understand the experience and health/support needs of British Armed Forces personnel/veterans with mesothelioma.

2. Methods

This qualitative study employed interviews with UK veterans and family members living with mesothelioma. Veterans were defined as "anyone who had served for at least one day in Her Majesty's Armed Forces (regular or reserve)" (Ministry of Defence, 2017). MiMES was approved by University of Sheffield Ethics Committee (application 020164).

2.1. Sampling and recruitment

Purposive sampling was used to ensure the sample included a range of patients and family members in terms of age, sex, time since diagnosis, geographical location and branch of service. We aimed to recruit up to 15 veterans and up to 15 family members. Based on existing literature and previous studies by the research team (Taylor et al., 2019; Warnock et al., 2019)this was considered sufficient to ensure data saturation, that is when no new themes are being generated from the data (Baker and Edwards, 2012; Higginbottom, 2004). In fact, data saturation was achieved with a smaller sample. The inclusion criteria stipulated that patient participants had to have a diagnosis of mesothelioma and have worked in the British Armed Forces. Family members had to have a family member living with mesothelioma who was serving or had served in the Armed Forces. Additional inclusion criteria for both patients and family members were that they did not consider themselves to be experiencing physical or emotional distress that would be aggravated by participation, they were able to give informed consent and speak English.

Invitations to participate in MiMES were circulated to veterans and family members via Mesothelioma UK and Asbestos Support Groups (ASGs). Mesothelioma UK is a national charity dedicated to providing specialist mesothelioma information, support and education, and to improving care and treatment for all UK mesothelioma patients and their family members .Information was distributed by Mesothelioma UK through newsletters and social media. People contacted the Mesothelioma UK information line if interested in participating. If contacted, information line staff discussed the study and liaised with the research team. Advice workers from ASGs discussed the study with veterans and liaised with the research team if the veteran or family member was interested in participating. An information sheet and consent form were then sent via post or email for the person to consider. No financial incentive was offered.

2.2. Data collection

Informed consent was obtained prior to the interview. Participants had an opportunity to discuss the study with a research team member. Semi-structured interviews were undertaken by SEM and BT between December 2018 and September 2019. All interviewers were female and were experienced in conducting in-depth qualitative interviews. Interviews lasted between 24 and 99 min. Twenty interviews were conducted over the phone and three were conducted in person. Telephone interviews enabled people to participate from across the UK, proved more convenient for interviewees and less burdensome. The telephone interviews afforded a high level of anonymity and privacy which enabled participants to disclose information about themselves (Cachia and Millward, 2011; Novick, 2008).

Interview topic guides (Box 1) were developed from the available literature and consultation with the project advisory group (Taylor et al., 2019; Warnock et al., 2019). Topics included the participant's demographic information, the veteran's service history, their journey from symptom to diagnosis, receiving a diagnosis, living with mesothelioma and their current health, treatment and care. All interviews were audio-recorded, professionally transcribed verbatim and then anonymised. Participant names included in this paper are pseudonyms.

2.3. Data analysis

The anonymised data were uploaded into QUIRKOS (a qualitative analysis software package). QUIRKOS was used to manage and search the data.

Thematic analysis methods were used to ensure a systematic and rigorous progression. Thematic analysis is a method of generating meaning and understanding from qualitative data through the identification of themes (Braun, V. & Clarke, 2006). Six analytical phases were conducted: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing a report (Braun, V. & Clarke, 2006).

After reading through the first three transcripts several times and making notes, initial codes were generated, and a provisional thematic framework was developed (by SEM, AT, BT, CW). This framework was uploaded to QUIRKOS and used to code the remaining transcripts. All data were then analysed by two researchers (by SEM, AT, BT, CW) themes were further developed and the thematic framework was revised. Themes were discussed at regular intervals and consensus was achieved through discussions with research team members (by SEM, AT, BT, CW, LD, AM). Emerging findings were discussed through consultation meetings with Mesothelioma Nurse Specialists, ASG staff and family members of people living with mesothelioma. This consultation provided an opportunity to challenge and verify the findings with a wider population.

3. Results

The final interview sample comprised 13 veterans living with

Box 1
Topic guide for interviews

Welcome and introduction.

Interview plan.

Confirmation of consent.

Statement of confidentiality.

Background information.

Age
Marital status
Living circumstances
Home: rural/urban
Other illnesses
Length of time since diagnosis (or length of time since family member's diagnosis)

Service history (own or family members).

Occupation
Where they were based
Length of service
Employment since leaving service
Awareness of asbestos exposure

Journey from symptom to diagnosis.

Symptoms
Interactions with family
Interactions with healthcare services

Receiving a diagnosis.

Initial response and reaction
Preferences for information
Interactions with family
Interactions with healthcare services

Living with mesothelioma.

Treatments received
Involvement in clinical trials
Experiences of navigating services
Claiming compensation
Sources of support

Current.

Health
Treatment and care
Support and information needs
Expectations and hopes for the future

Opportunity for additional comments.

Thanks for participation.

mesothelioma. Nine family members were also interviewed (Tables 1 and 2). The veterans' ages ranged from 61 to 89 and the family members' ages ranged from 36 to 74. Time since diagnosis ranged from three weeks to four years. While we attempted to recruit and interview women veterans, all veteran participants were men.

Table 1
MiMES patient participant characteristics.

Participant ID	Service	Telephone or face-to-face interview	Relative present (Yes/No)
Albert P1MN	Navy	Telephone	No
Bob P2MA	Army	Telephone	No
Callum P3MR	RAF	Telephone	No
Derek P4MR	RAF	Face-to-face	No
Errol P5MR	RAF	Telephone	No
Graham P7MR	RAF	Telephone	No
Henry P8MA	Army	Telephone	Yes
Ian P9MN	NAVY	Telephone	No
James P10MR	RAF	Telephone	No
Kevin P11MA	Army	Telephone	Yes
Leo P12MN	NAVY	Telephone	Yes
Martin P13MN	NAVY	Telephone	Yes
Neil P14MR	RAF	Telephone	No

First character: P= Patient.
Second character/s: Interview number.
Third character: M = Male.
Fourth character: Branch of service.
For example, Albert P1MN = Patient, Interview 1, Male, Navy.

Table 2
MiMES family member interviews.

Family members	Telephone or face-to-face interview	Relationship to person living with mesothelioma	Relative present
Paul F2MM	Face-to-face	Widower	No
Violet F3FC	Telephone	Wife of Henry P8MA	Yes
Naomi F4FC	Telephone	Wife of Kevin P11MA	Yes
Theresa F5FC	Telephone	Daughter	No
Josie F6FC	Telephone	Widow	No
Neville F7MM	Telephone	Widower	No
Simon F8MM	Telephone	Son	No
Orla F9FC	Telephone	Wife of Leo P12MN	Yes
Laura F10FC	Telephone	Wife of Martin P13MN	Yes

First character: F = family member of a veteran.
Second character/s: Interview number.
Third character: M = Male, F = female.
Fourth character: C = civil, M = military.
For example, Paul F2MM= Family member, Interview 2, Male, Military F1FC= Family member, Interview 1, Female, Civil.

The data indicated that many of the experiences of military veterans with mesothelioma reflect that of the wider population of people with mesothelioma (Hughes and Arber, 2008; Taylor et al., 2019). For example, the nature and extent of symptoms and the diagnostic process. This paper focuses on findings that relate to experiences that were influenced by having a military background. Three major themes were identified: (1) exposure to asbestos and awareness of asbestos related diseases; (2) using military strategies to cope with mesothelioma; (3) preferences for information and support.

3.1. *Exposure to asbestos and awareness of asbestos related diseases*

The findings provide understanding of the range and nature of exposure to asbestos in UK military veterans. There was wide variation across the sample in terms of the source of asbestos exposure (Table 3), but also variation in the awareness of the dangers of asbestos exposure.

3.1.1. *Sources of exposure*

Several participants had not worked directly with asbestos or in

Table 3
Suspected sources of asbestos exposure.

Participant pseudonym and ID	
Albert P1MN	Military service – removal of asbestos from ships
Bob P2MA	Military service – accommodation during training
Callum P3MR	Military service – looking after repairs, factory visits, working in Nissen huts
Derek P4MR	Military service – accommodation, rotor brakes in planes
Errol P5MR	Military service – sweeping up asbestos dust in accommodation
Graham P7MR	Military service – present when building work was undertaken
Henry P8MA	Military service – accommodation and working in bombed/disused buildings
Ian P9MN	Military service – extensive exposure on ships
James P10MR	Unknown
Kevin P11MA	Military service – living and working in bombed/disused building
Leo P12MN	Civil work – taking tea and lunch breaks in an environment with asbestos
Martin P13MN	Military service – insulating ships
Neil P14MR	Civil work - installing suspended ceilings, drilling through asbestos

occupations traditionally considered at higher risk of asbestos exposure, for example working in engine rooms on ships. Instead they recalled working and living in environments where asbestos was present. Therefore, asbestos exposure was not just due to occupation itself, but the buildings that veterans lived or worked in.

Exposure occurred both in the UK and while serving abroad:

> *"Henry: [In Kenya] we were staying in a big … shed, where the walls were made of asbestos. But it was asbestos and all our stuff is hanging next to it.*
>
> *[…]*
>
> *Violet: The pictures show he'd got his clothes like on hangers and personal things hanging from the asbestos, the corrugated asbestos." Henry, P8MA and Violet, F3FC*

> *"… all through the '70s, I was in and out of Northern Ireland all the time, living in old factories, bombed-out factories, dealing with bombs. And somewhere along the lines, I'd come in contact with asbestos. It could be debris from bombs in the air or anything." Kevin, P11MA*

Veteran participants who had served in Northern Ireland thought living and working in and near bombed buildings could be a potential source of asbestos exposure. The extensive international travel and proximity to buildings destroyed by bombs indicates how asbestos exposure for veterans diagnosed with mesothelioma may contrast to many civilians.

3.1.2. Awareness of the dangers of asbestos

Because the nature of the exposure was varied, most participants had not known the risk of asbestos at the time. However, after their military service, they had become aware of the dangers to asbestos. Awareness of asbestos risk occurred gradually over time through attending health and safety courses and hearing about the dangers of asbestos in the news. Some had heard that their fellow service men had been diagnosed with asbestos related diseases. For some, particularly naval veterans, this led to growing concern later in life that they would be affected at some point:

> *"I think he [a naval veteran] had a sense of, I thought this was going to happen anyway … my [other family member] has got asbestosis because he worked alongside my dad" Theresa, F5FC*

> *"… [after diagnosis] he just came home and said something like, oh, well, it's got me" Josie, F6FC*

As shown in the above quote, for many MiMES participants, their reaction to the mesothelioma diagnosis was more of resignation than shock. Military veterans, who have worked in high risk occupations and since known of fellow service men and/or their family members being diagnosed with mesothelioma may have a more resigned reaction at diagnosis.

3.2. Using military strategies to cope with mesothelioma

Veterans and family members used various techniques to cope with the challenges of living with mesothelioma. Participants' accounts indicated that their military identity and experiences influenced, in part, how they coped. For some it gave them a sense of strength which was demonstrated through their action-focused decisions and pride in maintaining independence.

3.2.1. Action focus at diagnosis

Many people invest in planning strategies immediately after life threatening diagnosis like mesothelioma. In this veteran population the tendency was more marked. An active and problem-solving approach to their diagnosis was present in nearly all of the participants' accounts. For some this included major life changes that were decided upon and actioned quickly and efficiently. Examples included moving across the country to be nearer family, or rapid decision-making with regard to particular treatments or clinical trials. Participants associated this problem-solving, solution-focused approach with their time in the Armed Forces, where often life or death decisions had to be made quickly and with confidence:

> *"… clearly we've got to move, make a decision and act on it quickly, given the prognosis … by the end of the weekend, we'd identified the house we're now living in, and then went on to buy it, and sold the house in [1st home town]. So, that was a major decision that we had to make." Callum, P3MR*

> *"When you're in a responsible position, as you know yourself, you either face up to it and you accept your responsibilities and you know that that may affect other people if you make the wrong decision, but you get on and do it anyway" Paul, F2FM*

Participants made comparisons between managing challenging experiences in the Armed Forces and living with mesothelioma. They drew on their military service experience and used this as evidence of their ability to cope in difficult circumstances. This provided strength and resilience to manage their mesothelioma diagnosis. Being action-focused and having a fighting spirit were linked to both their Armed Forces and mesothelioma experiences:

> *"I'm going to fight it. And the way to fight it is be a soldier" Bob, P2MA*

3.2.2. Pride in independence

Many participants described the importance of staying strong and being independent when coping and living with mesothelioma. These attributes were often directly linked to their military background and the culture of the armed forces.

> *"… it's the way I lived for 12 years [as a serviceman], I've always been independent … that's what they teach you in the military, don't they, to stand on your own feet and get on with it." Ian, P9MN*

However, this desire to be independent inhibited some participants from accessing emotional and physical support that they may have benefited from:

> *"The last thing my mother would have thought is when he [her father] was diagnosed, how can I get help, how can I be supported, how can we access better, you know, stuff, x, y, z. It would have just been 'you got to get on with it.'" Theresa, F5FC*

This attitude that military families should just "get on with it" was echoed in the accounts of the participants who were wives of veterans with mesothelioma. Some of the veterans' wives thought avoiding emotions was a useful and acceptable way for their husband to cope with the diagnosis. Another reason why veterans employed this coping strategy was because they thought it necessary to protect their wives and family. Both motives for this independent way of coping were, again, linked to the military experiences:

> *"Nowadays, you know, like the Afghan War and stuff like that, they go into decompression in Cyprus and they're forced to talk about it, which I really don't believe in. I think when you're ready for it to come out, then it needs to be dealt with at that point. If you're going to force something out, it's going to hurt more and you're going to re-traumatise that person. So that's kind of how I'm dealing with it, I'm locking it away until I need to sort it out." Naomi, F4FC*

> *"… when [husband] was off in a submarine for months on end, I was at home with a baby and a toddler, you know? Well, you can't put them in a cupboard or sit and cry because they won't go to sleep, you just do it. And you don't get a lot of help from the military, and you would never actually want to admit, especially being a senior officer's wife, you'd never want to admit, oh, I can't cope, because they would say, well, what's wrong with you?" Josie, F6FC*

Whilst to some extent coping independently, without outside help, was preferred or desired, support from others who had served in the Armed Forces was acceptable to some.

3.3. Preferences for information and support

3.3.1. The military family

The strong relationships that were formed from the shared experience of military service were important to many participants. This shared history facilitated connections, communication and trust between veterans. In later life, these relationships influenced who they turned to for support. Veterans and their families discussed the importance of contact with other veterans and military families – even if they had not served together:

> *"… you'd be talking with people who have all worked in the same industry together … So who have everything in common and talk the same language …" Albert, P1MN*

The sense of shared history meant that veterans living with mesothelioma relied on, and were willing to provide support for, each other. Providing support for others was linked to their sense of duty to and connections with others who had served in the military:

> *"… even if it's a little old man that comes round with his walking stick and medal on his chest and he says, I was a soldier, I'll sit and talk to him." Bob, P2MA*

Humour was one way in which veterans supported, and were supported by, others. A shared, and often dark, sense of humour underpinned the strong relationships between veterans. This sense of humour was often used to maintain levity in the context of living with a terminal disease. It appeared rooted in previous experiences where veterans had used humour to cope with precarious situations during their armed service:

> *"… you're making your will out, which we have to quite often, you know, [for] the Iraq war. And you sit next to your mate and you're filling your wills out, believe it or not, and you look at him and say, what size boots are you … We take the mickey out of each other but our hearts are together …" Kevin, P11MA*

3.3.2. Delivery of information from healthcare professionals

The specialist mesothelioma and asbestos related information and support provided by health professionals and other relevant organisations was valued by the participants. Many described how the specialist knowledge and efficiency helped them navigate the NHS.

> *"My current support comes from the mesothelioma nurse up here at [lung cancer specialist hospital] … she provides an interface if you like … I talk to her, and if it's something that the hospital needs to do, I can arrange an appointment, and she will do that. She'll get you in so to speak. So, she's key." Callum, P3MR*

Participants also expressed their preferences for the sources of information and timing of its delivery. There was a preference from all participants for clear and honest delivery of information. Even if the news was bad, most participants valued directness. However, there was also a desire for information to be delivered sensitively. This desire was frequently expressed by family members. The sensitive delivery of information was considered particularly important when professionals discussed asbestos exposure which may have occurred during combat. Revisiting such distressing times was seen to be a potential risk to psychological well-being:

> *"… she [the ASG professional] obviously had to say where do you think you got it from, so that did open the wound of Northern Ireland again. Any time he talks about Northern Ireland … it's going to slightly open that box again. So I think anybody who'd had that experience … would probably be struggling a little bit, I think." Naomi, F4FC*

3.3.3. Military and health systems

The participants drew a comparison between military organisations and the NHS and reported frustration from the latter, for the veterans were accustomed to a clear "chain of command" and standardised, national military systems. In contrast, participants provided examples of the NHS being less efficient and more difficult to navigate. Additionally, geographical variation in service provision within the NHS confused people:

> "*In the Armed Forces you have what they call a chain of command, but you don't step outside of your role. So you are responsible for whatever is in the square … So things are fairly definite in the way you deal with things." Paul, F2MM*

> *"… it's supposed to be the National Health Service but it's not national, the funding is not national and therefore the service is not centrally standardised. The MOD doesn't have those issues whether you're in the navy down in Cornwall, in Scotland or in London it's [the provision of service] the same." Simon, F8MM*

As mentioned previously, participants discussed turning to other veterans and military organisations for support, due to trust and shared prior experiences. In addition, military systems were viewed as easier to navigate than the civilian systems, such as those in the NHS. However, several veterans expressed frustration at the lack of support provided to them by the military organisations:

> *"I felt that the [military organisation], were the people who were going to give me the support, because they would understand … And now looking back, they probably wanted to, but they couldn't do any more than they did, which was not very much." Derek, P4MR*

Many participants described how individual healthcare professionals, particularly Mesothelioma Nurse Specialists, were essential in helping veterans access the care and support they required in a timely manner. This was especially important when they came across difficulties navigating care systems.

> *"I can't fault them at all … She [Meso UK nurse] was very good actually … after we finished with the oncologist we spent about half an hour with*

her. And, she went through all sorts of information, support information, contact information at the hospital, what to do next, sort of thing, and including contacting [local ASG]." Graham, P7MR

4. Discussion

4.1. Discussion of findings

MiMES provides unique insights into the experiences of UK veterans and family members living with mesothelioma and adds to the limited body of research exploring the lived experiences of those with mesothelioma (Abrahm, 2009; Ball et al., 2016; Taylor et al., 2019; Warnock et al., 2019). The majority of the mesothelioma population in the UK are men (83%) (Cancer Research UK, 2020). Therefore the existing published evidence on mesothelioma experience focuses on men. MiMES was able to generate evidence on the experience of male military veterans, compare this with the existing literature on men with mesothelioma, and identify differences between civilian and veteran men with mesothelioma. There is an increasing focus on promoting programmes and research that give UK veterans a voice and enable services to meet the Armed Forces covenant (Forces in Mind, 2019). MiMES provides such insight.

MiMES provided novel understandings of the nature and range of UK veterans' exposure to asbestos. The diversity of sources of asbestos exposure raises questions about the correct strategies to undertake effective occupational history taking. The findings highlight the importance of an occupational history being conducted by a professional with experience of working with veterans, and knowledge of asbestos and mesothelioma. Early referral to professionals with expertise in veteran occupational history taking has the potential to improve the care that veterans with a diagnosis of mesothelioma receive. Specific questions may need to be asked of veterans when taking an occupational history. Firstly, to determine if they have ever served in the Armed Forces and, secondly to identify the range of possible sources of exposure. Questions may include "Have you served abroad? Have you served in a combat zone?" It is then important to ascertain if asbestos exposure occurred solely within their military service or in their civilian life. The findings also suggest that, for some, discussion of exposure could bring back distressing memories and create additional emotional and mental health care needs. This further highlights the important role of experienced professionals when an occupational history is being taken with a veteran, and the need for referral options for psychological care if required. The quality of the occupational history taking can have both financial and emotional implications.

Participants discussed the ways in which their approach to living with mesothelioma was influenced by their time in the military. This might suggest that time in the military reinforces these particular aspects of men's practices, such as independence, control, and action orientation. The findings suggest that UK military veterans drew on their military service to generate the inner resources and resilience to cope with their mesothelioma. In this way their coping mechanisms differed from civilians. Some coping strategies were similar to civilians with mesothelioma. Previous research has highlighted that having a fighting spirit and prizing strength do feature in other illness responses and coping strategies (Czerw et al., 2016; Hodges and Winstanley, 2012; Hopman and Rijken, 2015). However, MiMES indicates that these attributes are especially prized in the military and can endure following service in the Armed Forces. In MiMES, veterans' and their families' responses to diagnosis were often action-centred with decisions rapidly made and executed. This reaction contrasts to the findings by Clayson et al. (2005) who found that patients living with mesothelioma reacted with stoicism but little action. These study findings indicate that by focusing on action, some veterans avoid an emotional response and enhance their sense of control.

A preference for a clear plan and information has been found by other studies exploring the experiences of people living with mesothelioma (Taylor et al., 2019). However, MiMES found that veterans and their families often linked this preference for clarity of information to their service history and the structure of military organisations. There is existing research that demonstrates how veterans may experience challenges in accessing services in civilian life, which can be more confusing and difficult to navigate (Wood et al., 2017). MiMES indicates that pride in independence may further inhibit veterans in explicitly asking for support. Service providers need to be aware of this and tailor care and support in a way that is accessible and acceptable to them.

The wider 'military family' was an important source of support for veterans and their families, due to a shared history, language and experiences. There is evidence to suggest that veterans may benefit from peer support (Brewster et al., 2020; Burnell et al., 2017a,b). The findings from MiMES align with this evidence. Community organisations could be a source of support for veterans living with mesothelioma, particularly as some participants appeared to gain strength from supporting other veterans. Some veterans may prefer to be supported by, and to support, those with shared military history and experience. Healthcare and ASG professionals need to be aware of this and refer on appropriately, for example to local veteran organisations.

Other studies of people living with mesothelioma also report to the challenges of navigating health systems (Clayson et al., 2005). MiMES shows that veterans may have to navigate both civilian health systems *and* military systems. Veterans with mesothelioma therefore have additional challenges to those of civilians as they have to work out which organisation is best placed to help them and when. As a result, veterans living with mesothelioma may need additional support to ensure access to the care and support they need from relevant organisations.

MiMES provides insights into how services may be developed to support veterans with mesothelioma. Evidence from the UK and abroad has shown that nurse specialists and navigators play a positive role in patient access and utility of healthcare systems (Bibby et al., 2016; Tod et al., 2015; Wagner et al., 2013; Warnock et al., 2019). MiMES highlights the role that Mesothelioma Nurse Specialists and ASG professionals play in assisting veterans and their families to navigate military and health services. Within the UK, there are mesothelioma nurses who focus on supporting Armed Forces personnel and veterans (Mesothelioma UK, 2018a). The Supporting Our Armed Forces service was launched by Mesothelioma UK in 2018 (Mesothelioma UK, 2018b). It is a UK-wide specialist service dedicated to raising awareness of the disease and supporting Armed Forces personnel and veterans. The contribution of these roles to the health and quality of life of UK Armed Forces personnel and veterans requires further study. Also worthy of further study is differences in perspectives between veterans and their family members. It was not the purpose of this study to compare the experiences of patients and carers. However, the authors acknowledge that this is an important area of research which requires further exploration.

4.2. Strengths and limitations

MiMES has generated novel insights into the UK veteran experience of mesothelioma. The inclusion of the carers' perspectives has enriched the findings. There are limitations related to the sample and the researchers' positionality. Mesothelioma is a relatively rare disease, so recruiting a large sample of veterans was always going to be challenging. However, including the family members of veterans with mesothelioma did add further insights and allowed us to triangulate the views of families with those of veterans. In addition, as both the military population and mesothelioma population are male dominated, we were unable to recruit any women to our study. The inclusion of women may have contributed to the richness of the study findings. Nevertheless, we were able to recruit a range of participants in terms of age, service branch, occupation within the service, and source of exposure. The range of participants also means that the study aim was achieved even though the sample size was small.

All interviews were undertaken by female researchers without an Armed Forces background. The researchers' gender and lack of a military background meant that they had an 'outsider' perspective. A researcher is considered an outsider when they do not belong to the community which they are researching (Dwyer and Buckle, 2009). This 'outsider' position may have been advantageous during data collection as it permitted the interviewers to ask questions that may seem obvious to someone who had served in the Armed Forces. This may have led to participants providing more detailed responses. There is also evidence to suggest that some men may feel more comfortable discussing their emotions and experiences with women researchers (Broom et al., 2009). Furthermore, the MiMES advisory board included veterans who helped develop the interview schedule and provided regular feedback on the developing themes. This ensured that the project was developed in conjunction with people with an Armed Forces background.

5. Conclusion

Research into the experience of military veterans and health care is limited in the UK. MiMES indicates that there are specific challenges and care needs related to veterans with mesothelioma. These may well apply to veterans with other oncology conditions. The study supports more research related to veterans living with other health conditions, including cancer, to understand better the care needs of patients and their families. MiMES findings have the potential to influence the care provided to veterans and their families. To facilitate this, the study team have worked with Mesothelioma UK to develop educational outputs and a report with recommendations for practice (Ejegi-Memeh et al., 2020) regarding care and support of veterans living with mesothelioma.

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CRediT authorship contribution statement

Stephanie Ejegi-Memeh: Investigation, Formal analysis, Writing – original draft, preparation, Visualization, Writing – review & editing, Project administration. **Liz Darlison:** Conceptualization, Writing – original draft, preparation, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Anne Moylan:** Conceptualization, Visualization, Writing – original draft, Writing – review & editing, Visualization. **Angela Tod:** Conceptualization, Methodology, Formal analysis, Validation, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Virginia Sherborne:** Writing – original draft, Writing – review & editing, Visualization. **Clare Warnock:** Formal analysis, Writing – original draft, preparation, Writing – review & editing. **Bethany Hope Taylor:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, preparation, Visualization, Supervision, Project administration.

Declaration of competing interest

No conflict of interest to declare.

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